Prescription for Physicians Suffering From Advocacy Deficit

The physician citizen has a long history of advocacy on behalf of patients. However, since workloads are larger than ever, many doctors have no time and suffer advocacy deficit.

When the Food and Drug Administration (FDA) reviewed interleukin 2 (IL-2) (in July 1990 and January 1992), the Biological Response Modifiers Advisory Committee held hearings at which the public was invited to make comments. Not one physician appeared before the committee to comment about IL-2. What does the silence of so many physicians mean? Doctors regularly ask patients to endure clinical trial medicine. When new drugs come before the FDA, shouldn’t patients expect physicians to testify on behalf of patient needs?

Symptoms of advocacy deficit include an unbalanced work life, reduced compassion, confusion over public policies in health care, failure to help patients with the socioeconomic problems of illness, and having no time for patient questions.

Fortunately, patients have become their own advocates. Yet physicians remain isolated. There are three obstacles to treating advocacy deficit: 1) fear that patient advocacy will increase malpractice litigation, 2) fear of having diagnoses and recommendations challenged by well-informed patients or “problem” patients, and 3) lack of familiarity with patient advocacy organizations.

Effective treatment for advocacy deficit begins with knowledge. Physicians must identify and know advocates in their field. The National Kidney Cancer Association, for example, publishes two newsletters, 1) We Have Kidney Cancer and 2) Kidney Cancer News. It is involved in the application of in vitro drug testing on kidney cancer as well as in advocacy. Cancer Care, an organization in New York City, provides information on social services. Representatives from Patient Advocates for Advanced Cancer Treatments and the National Coalition for Cancer Survivorship (NCCS) have testified before Congressional committees. Representatives from the National Kidney Cancer Association and Cancer Patients Action Alliance (CAN ACT) testified before the FDA and were instrumental in the approval of IL-2.

The next step in the treatment of advocacy deficit is joining the advocacy organization. However, passive involvement is not curative. A lasting cure for advocacy deficit requires the physician to join the board or to serve in an advocacy organization. Physicians should attend patient meetings, edit booklets, and write position papers for the government. A financial contribution to the patient advocacy organization can also be part of the “cure.” Investing capital is an important commitment, but do not confuse writing a check with a commitment of “self.”

Another step in healing the physician is demonstrating trust. The physician does this by prescribing membership in the advocacy organization to his or her patients. Just as a physician can prescribe a drug, a physician can also prescribe active involvement so that the patient can help himself or herself.

Too often, patients and physicians settle for emotional support. Morphine for the mind is no substitute for action, such as getting a new drug approved by the FDA. The best emotional support is often channeling the anger and fear of the cancer experience into constructive action.

In some cases, lives are saved. For example, one patient had recurrence of his cancer at the site of his kidney after nephrectomy. His surgeon removed the recurring tumor, but 1 year later, it returned. The patient was sent to an oncologist who prescribed IL-2 followed by interferon and floxuridine. Nothing worked. At a local meeting of the National Kidney Cancer Association, the patient saw a presentation describing surgery as a treatment for metastatic disease. Two years later, after new surgery by a different doctor, the patient remains tumor free. Informational meetings for patients can be a powerful survival tool.

There are definite benefits for physicians who are involved in advocacy (such as referrals and faster accruals for clinical trials). The physician who is fully recovered from advocacy deficit shows robust signs of life. He or she stands up for patients in public forums.

If you suffer from advocacy deficit, heal thyself with the prescription outlined here. But recognize that this cure does not come cheaply. You are advised to make an honest investment of self, money, and time.

EUGENE P. SCHONFELD, PH.D.
President and Chief Executive Officer
National Kidney Cancer Association
Suite 200
1234 Sherman Ave.
Evanston, IL 60202

Erratum: “Prospective Study of Plasma Fatty Acids and Risk of Prostate Cancer,” by P. H. Gann, C. H. Hennekens, F. M. Sacks, et al. [J Natl Cancer Inst 86:281-286, 1994 (Issue 4)]. The authors wish to correct an error: “The ‘Patients and Methods’ section (p. 282) states that plasma fatty acid composition was measured in the cholesterol ester lipid fraction. However, the data in the report refer to fatty acids in the phospholipid fraction. The relative amount of individual fatty acids does vary according to the lipid fraction in which they are measured. However, fatty acid levels in both cholesterol ester and phospholipid fractions are responsive to general dietary patterns, and it is not clear which fraction might be more relevant in the etiology of prostate cancer. Plasma phospholipids are thought to be involved in a dynamic equilibrium with phospholipids in erythrocyte, and possibly other, cell membranes. We are currently completing an analysis of fatty acid composition in the cholesterol ester fraction of the same plasma samples.”